

Box 4: Examples of tools for assessing the quality of consumer health information

DISCERN (www.discern.org.uk)—developed to assess the quality of health information on treatment choices.^{13 14} A number of hints are given after each question to guide the user. Areas covered are: bias in the material, a clear statement of aims, references and additional sources of support and information, uncertainty, risks and benefits (including those of opting for no treatment), and treatment options. DISCERN also alerts the user to concepts such as shared decision making, and quality of life. An online version (www.discern.org.uk) is currently being tested.

The Health Information Quality Assessment Tool (hitiweb.mitrotek.org/iq)—the Health Summit Working Group in North America (hitiweb.mitrotek.org/hswg) is currently developing a reliable and valid appraisal tool for users of health information on the internet.¹⁵ The tool is interactive and is potentially useful for patients wishing to evaluate the overall quality of health related websites. The main areas currently covered are credibility, content, disclosure, links, design, interactivity, and caveats (information on the function of the site).

leaflets for patients, Smith emphasised the time it takes to produce clear, unambiguous material that patients will use.²⁰ In addition to following validated quality criteria, writers should take patients' information needs into account and be aware of how people will read what they have written.^{21 22} This will require involving patients in developing and testing materials.¹⁰ Before embarking on this lengthy process, however, a first step is to check if high quality information already exists.

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Framework for teaching and learning informed shared decision making

Angela Towle, William Godolphin

Faculty of Medicine,
University of British
Columbia,
Vancouver, BC,
Canada V5Z 4E3
Angela Towle
director, MD
undergraduate
programme

Department of
Pathology and
Laboratory
Medicine,
University of British
Columbia
William Godolphin
professor

Correspondence to:
A Towle
atowle@interchange.ubc.ca

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Patients should be involved in making decisions about their health care. The ethical imperative of autonomy is reflected in legal trends that require a high standard of disclosure for informed consent, amounting to a principle of informed choice.¹⁻³ Outcomes of care and adherence to treatment regimens improve when patients are more involved.^{4 5} Consumerism is part of the social spirit, and governments exhort citizens to take more responsibility.

Models of doctor-patient encounters that result in increased involvement of patients and that are informed by good evidence have been termed, for example, "informed patient choice"⁶⁻⁸ but do not describe the interactive process clearly. We use the term informed shared decision making to describe decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient specific characteristics and values. It occurs in a partnership that rests on explicitly acknowledged rights and duties and an expectation of benefit to both.

We propose that a demonstrated capacity to engage in informed shared decision making is charac-

Summary points

Competencies for the practice of informed shared decision making by physicians and patients are proposed

The competencies are a framework for teaching, learning, practice, and research

Challenges to putting informed shared decision making into practice are perceived lack of time, physicians' predisposition and skill, and patients' inexperience with making decisions about treatment

terised by a set of necessary and sufficient competencies. By competencies we mean the knowledge, skills, and abilities that represent the instructional intents of a programme, stated as specific goals.⁹ They are a framework for teaching, learning, practice, and investigation

of what should be a coherent process and an accomplishment of any doctor-patient encounter in which a substantive decision is made about treatment or investigation for which reasonable choices exist. They are mainly related to communications skills, but at a higher level than those typically taught in medical schools and continuing medical education, where the emphasis tends to be on obtaining information from patients (diagnostics), breaking bad news, and health promotion. We present them with an intent of parsimony and coherence. The sequence is not intended to be prescriptive, nor do they describe verbal phrases or a check list of behaviours. The time and attention paid to the separate elements will vary with circumstances; they may occur over several encounters and will probably be iterative.

It seems logical that if informed shared decision making takes place in partnership then patients should bring certain abilities to the encounter. If the sole responsibility for informed shared decision making rests with physicians then we tend to perpetuate the paternalistic "doctor knows best" relationship. Others (such as a doctor's nurse or receptionist and a patient's spouse or parent) may also make important contributions to informed shared decision making. Although our work has mainly focused on the development of competencies for physicians, we have developed a preliminary set of complementary competencies for patients.

Methods

We performed a literature search using electronic databases (Medline, CINAHL, and HealthSTAR) and references listed in textbooks to produce a draft list of competencies. We then tested their validity in semistructured interviews with five family doctors, four patients, and three patient educators (health professionals whose role is to educate and counsel patients about their condition) who were identified by their peers as having good communication skills. We also tested the validity of the competencies in focus groups with cancer patients, diabetic patients, and patient educators.

Physician competencies

We defined a working set of eight competencies for physicians through the literature review, interviews, and focus groups (see box). The basic concepts inherent to informed shared decision making, and thus underlying the competencies, are partnership (competency 1), explicit dialogue (all, but especially 2 and 3), an informed patient (4 and 6) and physician (4 and 5), shared decision making (6 and 7), and completeness.⁸

Partnership

The defining characteristics of partnership derive from the models of mutual participation and contracts.¹⁰⁻¹² From the literature and our interviews and observations, we conclude that partnership

- Implies mutual responsibilities (both physician and patient have something to gain and contribute)
- Requires attention to, and explicit discussion about, the relationship
- Is dynamic and adapts to changing circumstances of either party

Competencies for physicians for informed shared decision making

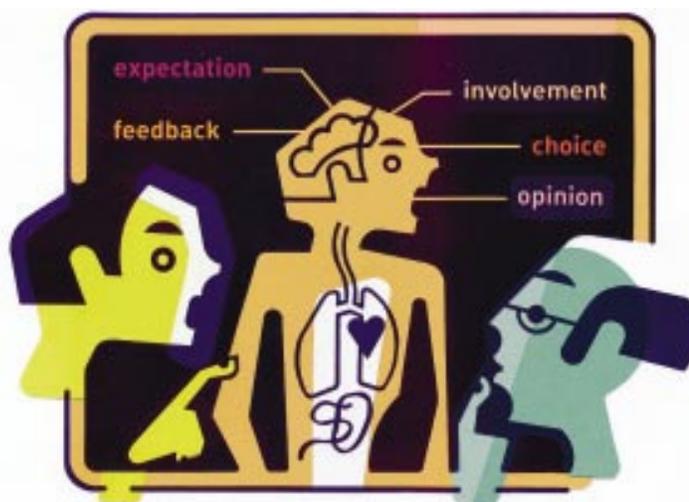
- 1 Develop a partnership with the patient
 - 2 Establish or review the patient's preferences for information (such as amount or format)
 - 3 Establish or review the patient's preferences for role in decision making (such as risk taking and degree of involvement of self and others) and the existence and nature of any uncertainty about the course of action to take
 - 4 Ascertain and respond to patient's ideas, concerns, and expectations (such as about disease management options)
 - 5 Identify choices (including ideas and information that the patient may have) and evaluate the research evidence in relation to the individual patient
 - 6 Present (or direct patient to) evidence, taking into account competencies 2 and 3, framing effects (how presentation of the information may influence decision making), etc. Help patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle
 - 7 Make or negotiate a decision in partnership with the patient and resolve conflict
 - 8 Agree an action plan and complete arrangements for follow up.
- Informed shared decision making may also:
 - Involve a team of health professionals
 - Involve others (partners, family)
 - Differ across cultural, social, and age groups

- Can be initiated at any time, but takes time to develop; most encounters ought to provide opportunities for partnership building
- Is key to the other informed shared decision making competencies.

Explicitness

In the absence of explicit discussion, physicians make incorrect assumptions and unilateral decisions about patients' information needs and preferences, and incorrectly assess their own information giving behaviour.¹³⁻¹⁵

A consistent theme in the literature is that patients want more information than they get, although studies on patients' preferences for decision making show more variation. The obvious solution is to engage in an explicit



MARK HUDSON

Competencies for patients for informed shared decision making*

- 1 Define (for oneself) the preferred doctor-patient relationship
- 2 Find a physician and establish, develop, and adapt a partnership
- 3 Articulate (for oneself) health problems, feelings, beliefs, and expectations in an objective and systematic manner
- 4 Communicate with the physician in order to understand and share relevant information (such as from competency 3) clearly and at the appropriate time in the medical interview
- 5 Access information
- 6 Evaluate information
- 7 Negotiate decisions, give feedback, resolve conflict, agree on an action plan

*Preliminary list

discussion. Preferences should be rechecked since needs vary over time and at different stages of illness.¹⁶ Some decisions are inherently more difficult, and uncertainty remains about the course of action to take—for example, because of a lack of information about alternatives and consequences, emotional distress, or perceived pressures from others.¹⁷ Through discussion the physician may help to clarify the existence, nature, and degree of these uncertainties.

The informed patient

Patients bring information to the consultation that needs to be shared. In relation to decision making patients bring three perspectives to the problem: information, expectations, and preference.¹⁸ Eliciting these concerns, ideas, and expectations is at the heart of patient centred care (finding common ground)¹⁹ and again needs to be done explicitly. The patients we interviewed gave examples of how doctors make assumptions and inaccurate guesses about patients' concerns,²⁰ and there is always the potential for misunderstanding. For example, a reassurance such as "It's nothing to worry about" may be interpreted as ignoring important anxieties.

The informed physician

Physicians need to be able to find and evaluate current evidence.^{21 22} Two points emerged from our interviews: the patients assumed that this is what doctors do already, and they wanted physicians to consider all options available (not just drugs) including those suggested by the patient. Alternative and complementary therapies are a challenge. The patients noted that physicians are often not open to or informed about such therapies ("Saying 'It can't do you any harm' is no discussion"), and there is rarely any evidence about their efficacy. Even if these are not included as valid choices they cannot be ignored. Many patients contemplate and use them, and only a minority disclose this to physicians.²³

Shared decision making

A rich and complex literature on decision making, decision analysis, communication of risk information, and framing effects underlies this competency.^{24 25} Theories about decision making suggest that people do not have stable and pre-existing beliefs about self interest but construct them in the process of eliciting information or deciding a course of action.²⁶ The way

information is provided by the physician is therefore crucial in assisting patients to construct preferences.

Practising the competencies for informed shared decision making should lead to an agreed decision. Problems may arise if there is no obvious best option (for example, because of lack of good evidence) or disagreement about the best option. Physician and patient are then in conflict, and a solution needs to be negotiated. If decision making is not explicit, conflict may go unrecognised by the physician, with consequences such as patient dissatisfaction and non-adherence with treatment. In the context of informed shared decision making, we take negotiation to mean "a back and forth communication designed to reach an agreement when you and the other side have some interests that are shared and others that are opposed."^{27 28}

Completeness

Informed and shared decisions do not just happen. Both parties need to be clear on what decision has been made, the plan to carry it out, the expectations, roles and responsibilities, and arrangements for follow up.²⁹ All encounters for informed shared decision making should conclude with an action plan. This may range from an informal verbal agreement to a formal written contract.

Patient competencies

In the absence of good literature on communication skills for patients, we asked our informants what patients should be able to do to play their part in informed shared decision making. The family physicians found it difficult to identify specific skills that patients should possess, but the patient educators and patients (particularly those with chronic diseases) had many suggestions, which we distilled into a preliminary set of competencies (see box).

Patients who are active in managing their health and illness are also active in managing the relationship with their doctor.³⁰ The patients with chronic conditions confirmed that they learn how to engage in partnership and improve their communication through experience. Patients can be taught these skills formally,³¹⁻³³ although experiments have been piecemeal. The refinement of patient competencies and ways to teach them are major challenges for successful implementation of informed shared decision making.

Other challenges

We have met three recurring objections in the course of our work.

"It would take too much time to do all that"

Several studies have shown that doctors trained in some of these communications skills do not take significantly longer to conduct patient interviews.³⁴⁻³⁶ An encounter involving informed shared decision making may take longer but may still be more efficient because of improved health outcomes. Well developed skills may permit time savings. These are research questions. Our preliminary experiments with standardised patients (patients or actors trained to present with a consistent history) and physicians willing and

able to practise informed shared decision making suggest that competence in such decision making can be demonstrated in a 10 minute encounter.

"But we [physicians] already do that"

There is a wealth of somewhat depressing evidence that physicians and patients do not communicate well. Patients rarely give direct feedback about communication problems. This may encourage physicians to believe that the studies do not apply to them personally. Skills in communications and critical appraisal can be improved by training. In our experience the use of standardised patients with common problems has the advantage that good communications are focused on improved health outcomes, and physicians tend to be more accepting of, and responsive to, feedback about communications from patients (even standardised patients) than from peers or educators.

"What about patients who don't want to be involved?"

Specialist knowledge and the law create an imbalance in the power relationship between physician and patient. Any shift from a paternalistic physician practice toward a "meeting between experts"³⁷ requires the physician to encourage patient autonomy.³⁸ Most studies and theories of shared decision making are illustrated by "hard cases"—that is, situations in which decisions are for high stakes (such as treatment options for cancer). If physicians and patients are to become proficient at making informed and shared decisions it would be sensible to begin with common problems.³⁹ We are not surprised that patients shun making decisions about treatment for breast cancer if their prior experience gave little opportunity or encouragement in relatively minor medical situations.

Our informants noted the much commoner occurrence of elements of informed shared decision making in encounters about chronic disease such as diabetes or arthritis. Presumably, practice improved performance. Social, cultural, and language factors may be barriers to putting informed shared decision making into practice, but these probably occur as serious problems in only a minority of encounters for most physicians, and possible solutions have been proposed.⁴⁰ There are many situations in which informed shared decision making could be practised, in which patients wish it were practised, and in which the major barriers are lack of predisposition and skill.

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Commentary: Competencies for informed shared decision making

Trisha Greenhalgh

Department of
Primary Care and
Population
Sciences, Royal Free
and University
College Medical
School, London
N19 3UA

Trisha Greenhalgh
senior lecturer in
primary care

p.greenhalgh@ucl.
ac.uk

As Towle and Godolphin have shown here, the best way to define the competences for a particular job is to ask the people who do it best, as well as those on the receiving end of the goods or services, and to use a second round of interviews to gain feedback on a first draft.¹ We are given few details of the recruitment methods used in this study, but it comes as no surprise that important outputs from health professionals for informed shared decision making include developing a partnership with patients, establishing their preference for the amount and format of information, finding and evaluating evidence on the different options, and presenting the data to patients in a way that doesn't blind them with science.

I have three main difficulties with this paper. Firstly, while it is useful to have the competences (outputs) for informed shared decision making spelt out, Towle and Godolphin seem to confuse these outputs with the component competencies (inputs) that might be expected to produce these outputs (and which might be improved by training). For example, we can infer obliquely from this article that the core competence "Develop a partnership" requires a number of separate inputs, which include being prepared to take responsibility (for this task), being able to communicate ("discussing the relationship") with a patient, and being sensitive (to the patient's changing circumstances)—but who is to say that these inputs are sufficient as well as necessary to produce that output, or that the same outputs could not be obtained from a different combination of inputs? The core competence "Identify choices and evaluate evidence" is given little attention here, yet there are probably over 20 separate inputs in terms of knowledge, skills, and attitudes required to achieve this complex task effectively.²

My second reservation concerns the theoretical notion of professional competency, which Towle and Godolphin treat as entirely unproblematic. Others have argued that the deconstruction of professional competence into component competencies is a flawed approach, being based on a behaviourist (and therefore

reductionist), task oriented model that ignores the complexities of clinical practice.³⁻⁶ Tanenbaum talks of the "practical wisdom" that forms the bedrock of clinical experience and which simply cannot be broken down into a straightforward cluster of tasks or traits.⁷ I have argued elsewhere that the "competencies" model, extensively used in the industrial and commercial sectors, should not be grafted wholesale onto the performance of health professionals.²

Finally, this paper lacks a clear statement of how Towle and Godolphin's lists of "competencies" (strictly, competences) should be used. The eight for health professionals might, for example, be used to define professional standards, provide selection criteria, set training targets, or manage performance. Those for patients might inform the design of educational materials—but they could potentially be misused if they led to patients being formally defined as "not competent" for informed shared decision making (akin to being branded a "poor historian").

The fact that professional practice is difficult to define and impossible to deconstruct should not stop us from using sentences which begin, "The competent health professional should be able to ...". Despite its limitations, Towle and Godolphin's analysis is an important first step towards a systematic approach to recruitment, training, and professional development in shared decision making.

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Commentary: Proposals based on too many assumptions

Jeremy Gambrill

67 Brighton
Cottages, Cuckfield
RH16 1XT

Jeremy Gambrill
cancer patient

gambrill@
netcomuk.co.uk

From a patient's perspective, the outline premise of Towle and Godolphin's article is most welcome, but there are some major assumptions made that make informed shared decision making look a practical impossibility.

The most immediate issue is the presumption throughout of a "one to one" relationship between doctor and patient. Nothing in the article addresses patients' access to their general practitioner. To cite my personal experience, my general practitioner's practice has four doctors. With whom should the doctor-patient

relationship exist, given that I might need speedy access to a doctor and that the general practitioner of my choice may, understandably, not be available on demand? Furthermore, what price the quality of informed shared decision making once patients leave their general practitioner's direct care, such as when they are referred to a specialist? Since my prostate tumour was diagnosed, I have been seen by a surgical urologist (twice), his locum (once), a clinical oncologist (twice), and her two locums (once each). How can there be a close working relationship between patient and

physician in such circumstances? And of course, each consultation, scan, treatment, or whatever requires a follow up consultation at my general practice, where it is quite likely that the general practitioner who referred me is not the general practitioner who deals with the consequences of the referral.

Towle and Godolphin make much of the need for patients to formally take a measure of responsibility in planning their treatment, and this requires that they are well informed about their condition and possible treatment options. Excellent. In my case I can and do monitor the scientific and academic press, websites, and news groups to stay aware of any developments that may have a bearing on my future treatment. But this is only possible because I am 51 years old, literate, articulate and have access to and an understanding of the techniques of information gathering and evaluation. What chance is there for elderly, poorly educated, and socially disadvantaged patients with the same condition that I have? Must they rely on the posters on their general practitioner's surgery wall?

Furthermore, not all patients will see informed shared decision making as desirable. Many patients— young and old—much prefer to believe that “Doctor knows best,” and this cannot be lightly dismissed, even though it might be unacceptable to Towle and Godolphin, and perhaps to many other doctors. For such patients, informed shared decision making will be seen as doctors opting out of their responsibilities rather than an improvement in the doctor-patient relationship.

Finally, I wonder how such a tiny sample size of physicians, patients, and “patient educators” can be cited as valuable in making “a set of necessary and sufficient competencies.”

Desirable though it might be for some patients to be more closely involved in managing their condition, the authors' suggestion that informed shared decision making become standard working practice presumes too much about the role of patients.

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Acknowledging the expertise of patients and their organisations

Judy Wilson

The proportion of people living with a long term medical condition, both in the United Kingdom and throughout the world, is rising.^{1 2} By living with and learning to manage a long term illness many people develop a high degree of expertise and wisdom. This article suggests ways in which people with a long term medical condition and their organisations can help develop partnerships between healthcare professionals and patients and questions how much their potential contribution is appreciated and capitalised on.

The US Centers for Disease Control and Prevention defines chronic diseases as “illnesses that are prolonged, do not resolve spontaneously and are rarely cured completely.”³ The Long-term Medical Conditions Alliance is developing a much broader definition that emphasises the effect that this type of illness has on people's emotional and social wellbeing; on their social, community, and working lives; and on their relationships. The alliance's definition emphasises the opportunities available to improve a person's quality of life, even when there is no cure for a particular condition. All these issues must be taken into account in planning when assessing a person's needs and how best to meet them.

The Long-term Medical Conditions Alliance is the umbrella body in the United Kingdom for 96 national voluntary organisations. Formed initially because of concerns arising from the reforms to the NHS in 1990, during which market principles were adopted to increase the efficiency of the service, the alliance enables organisations to work together to gain mutual support, to identify common concerns, to develop solutions, and to influence policy and practice.

Summary points

People living with a long term illness develop expertise and wisdom about their condition and want to play a part making decisions about their own health care

Partnerships should be encouraged between individual patients and healthcare professionals and between patients' organisations and the healthcare system

Developing partnerships between patients and healthcare professionals is not good in itself but offers a chance to improve health care and to make better use of resources

Partnerships can only be developed if there is investment by governments, if patients' capacity for self care is increased, and if the role of patients' organisations is developed

The Long-term Medical Conditions Alliance, London EC1N 7RJ
Judy Wilson
director
alliance@lmca.demon.co.uk

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Partnerships between individuals

The concept of patients working in partnership includes the idea of patients working with healthcare professionals. Research in the Netherlands has shown that people with a long term condition want their relationships with clinicians to be based on mutual trust and respect. Most want to be responsible consumers of health care if the providers of that care create an environment in which patients receive guidance when choosing between alter-